



Our Case for Support



PEDIATRIC EPILEPSY SURGERY ALLIANCE

Providing a Compass for an Unimaginable Journey

Your newborn son's eyes roll back and his body shakes. He's rushed to the neonatal intensive care unit. After days of exhaustive tests, doctors confirm that half his brain is malformed and it's causing hundreds of seizures a day. Medications fail to help, leaving him facing an **uncertain future**.

The doctors present a potentially transformative yet severe option: a hemispherectomy, the removal of one half of his brain.

As absurd as this may be, **this is Henry's story**.

Henry is one of 40,000 children in the United States who are diagnosed with epilepsy each year. Unfortunately, **one out of three children with epilepsy have seizures that medications cannot control**. This can lead to a lifetime of challenges including developmental arrest, brain damage, and even death.

For decades, brain surgery was considered a last resort, but that's no longer true. Surgery is often the best way to improve a child's **quality of life**.



Henry Jones after his hemispherotomy at 3 months old



The Jones Family in 2017

Transforming Grief Into Hope

Founded in 2011 by Monika and Brad Jones after their son, Henry, required a hemispherectomy, the organization, then known as The Brain Recovery Project, aimed to fund research to improve outcomes after surgery. Over time, we recognized that the entire community of children who need some type of neurosurgery to treat their seizures was underserved. The organization shifted its focus to helping families understand **when it's time to consider epilepsy surgery** and now offers programs to help caregivers navigate **therapies, development, school, and learning after surgery**.

Now, as the Pediatric Epilepsy Surgery Alliance, we are a **trusted source of information** for parents and caregivers before and after epilepsy surgery. We're with our families every step of the way from the point of drug-resistance through the transition to adulthood and beyond.

Our mission is to **enhance the lives** of children who need neurosurgery to treat medication-resistant epilepsy by empowering their families with research, support, and impactful programs before and after surgery.





We envision a world where all children after epilepsy surgery have the opportunity for a high quality of life, including an appropriate education, gainful employment, meaningful social opportunities, and good health to the maximum extent possible regardless of where they are on the spectrum of outcomes.

Taylor had left frontal and temporal lobectomy for seizures caused by cortical dysplasia. She loved the giant swing at our 2022 family and research conference.

Empowering Families with Knowledge and Support

The Pediatric Epilepsy Surgery Alliance is the **only** nonprofit organization focused on children who need neurosurgery to treat their seizures. We are a caregiver-led, science-driven organization with lived experiences of the pediatric epilepsy surgery journey.

Our two main goals are: 1) to **empower families** with research, support services, and impactful programs, and 2) to foster new **knowledge and understanding** of the functional impacts of pediatric epilepsy surgery through patient-focused research. This work is accomplished thanks to advocacy and collaboration among volunteers, families, and clinicians.



There's nothing
else like it.

Families enjoying the dance party
at our biennial family and research meeting.

What We Do

Resource Hub



Our website, webinars, and toolkits serve as **comprehensive guides** for parents, caregivers, and educators. From **information** about when it's time to consider surgery through the transition to adulthood and beyond, we're a **trusted source** for our community.



Parent Support Navigators

We have 24 parent support navigators trained in evidence-based peer support practices, and who are ready to offer immediate, **personalized guidance** and **emotional support** to parents and caregivers. Our support navigators speak various language.



Financial Aid

Up to \$1,000 in travel costs for families who need to travel for surgical evaluation and are facing geographic or **financial barriers**.



Research

We inspire and fund research to understand and improve outcomes after surgery, including our Global Pediatric Epilepsy Surgery Registry this research initiative allows families to share their experiences with and without epilepsy surgery in childhood by completing a series of surveys. The result is '**research-ready**' data to report back to other parents, neurosurgeons, neurologists, and aligned professionals like physical therapists and educators who care about the benefits and challenges after epilepsy surgery.



Educator Training

A history of seizures and epilepsy surgery may result in side effects that influence a child's academic performance. We equip educators with **specialized training** to better support the child's educational journey towards success.

Phin's Story



I found the Alliance on my quest to consume and learn as much as I could about epilepsy surgery, its complications/benefits, and outcomes. I watched every video pertaining to how my son's journey unfolded. I particularly liked the interview videos with a neurosurgeon breaking down the processes and branches of why certain tests were important.

Phinneas had laser ablation of brain tissue to treat seizures caused by a stroke

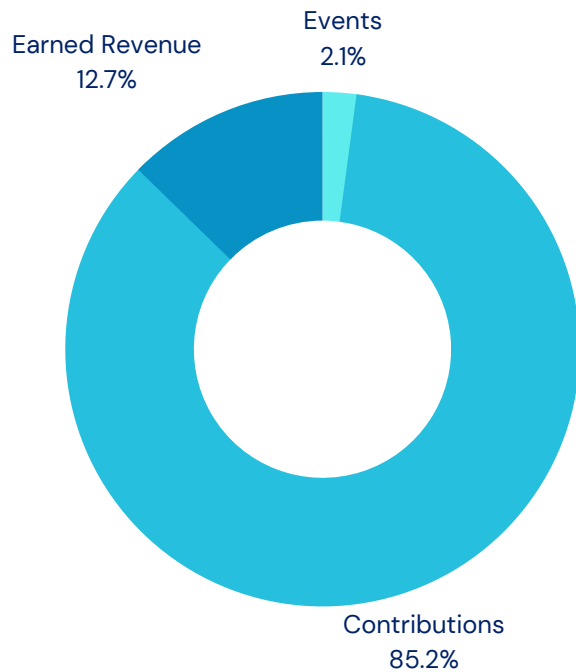
The stereotactic EEG information I referenced repeatedly since my son was admitted for 17 nights and ended up needing neurostimulation to complete the study.

I also took advantage of the peer-to-peer support and love when I get to talk to Audrey. She is very validating and the support of another parent cannot be measured.

No one would wish to have their child or another family go through these things. **The Alliance is the closest thing to providing a flashlight during a scary time when times feel dark.** I hope doctors and centers start pointing families to them, because I found them by chance.

-Phin's mom

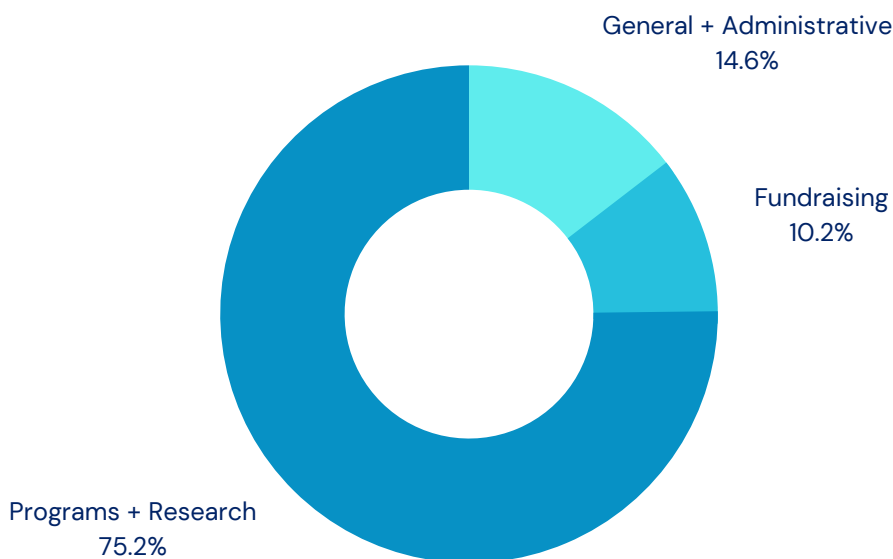
Financials



Revenue

• Events	\$6,907
• Contributions	\$278,182
• Earned Revenue	\$41,501

Total:	\$326,590
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Expenses

• Programs + Research	\$262,723
• General + Administrative	\$50,907
• Fundraising:	\$35,803

Total:	\$349,433
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Help Us Expand Our Impact

The Alliance is at a critical moment in its history. As programming has expanded, so has the need to streamline our internal structure and **lay a solid foundation for sustainable growth.**

Embarking on our second decade, our vision is guided by a board- approved strategic plan that focuses on factors that contribute to children having the best chance at a **high quality of life** after neurosurgery to treat seizures.

This focus grew out of a survey aimed to address the unique needs of our community and is informed by our volunteers on the Scientific Advisory Board, which is made up of clinicians who provide guidance and direction for our research agenda, and our Community Advisory Council, comprised of parents/guardians of individuals, and adults, who had epilepsy surgery in childhood and can provide insight on community concerns before and after epilepsy surgery in childhood.

Through our expansion, the Alliance is **poised to make an even greater impact** in the years to come, and more effectively provide support, guidance, and evidence-based research to help families navigate every step of the epilepsy surgery journey and beyond.

Your Partnership

We need your help to **serve more families** facing this unimaginable journey. Because our programs are offered at no cost to participants, **we rely 100% on philanthropic support to sustain our mission** and help us reach a critical number of parents and clinicians in their communities.

Your support enables us to actualize our vision, **scale up program offerings across the country**, and ultimately **reach and transform more lives.**

Please consider making a gift today. Stand with our families as they navigate the unimaginable.

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**pediatric epilepsy
surgery alliance.** 
RESEARCH • INFORMATION • COMMUNITY

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